

WEBSITES: FAMILIES/PROFESSIONALS (English)

► Web Transition Resources Targeted toward Families and Others

AAP Build Your Own Care Notebook –

http://www.medicalhomeinfo.org/for_families/care_notebook/

Sponsored by the American Academy of Pediatrics as part of the web site for the National Center for Medical Home Implementation, this site provides a wealth of resources to help families prepare and maintain a care notebook. Categories of sample forms include cover pages, personal information, appointment scheduling and information, personal notes, care needs, community health care service providers, and school issues. It allows parents to select from many different versions of existing care notebook forms and put them together to create a customized care notebook. Some materials are available in both English and Spanish.

Adolescent Health Transition Project – depts.washington.edu/healthtr/

Sponsored by the Children with Special Health Care Needs Program of the Washington State Department of Health, the site is housed through the Center on Human Development and Disability (CHDD) at the University of Washington, Seattle. This site is a resource for information, materials, and links to other people with an interest in health transition issues. Some of the topics included are: information targeted toward providers and educators, parents and families, or teens and young adults; a transition timeline and an adolescent autonomy checklist; a transition resource notebook; and a health history summary form for teens. Transition timelines are available in English, Spanish, Vietnamese, Russian, and Chinese.

Annie E. Casey Foundation Publications – <http://www.aecf.org/KnowledgeCenter.aspx>

Sponsored by the Annie E. Casey Foundation, a private, not-for-profit organization, devoted to serving children in foster care and children who are at risk for poor educational, economic, social, and health outcomes. The publications web pages offer printed resources on a wide variety of topics and include a page for Foster Care/Youth Transition/Youth Development. Publications may either be downloaded or ordered free of charge through the web site..

DSCC Transition Information and Resources –

<http://internet.dsccliu.edu/dscclroot/parents/transition.asp>

Established in 1937, and administered by the University of Illinois at Chicago, the Division of Specialized Care for Children (DSCC) is the Illinois Title V agency that provides care coordination for families and children with special health care needs. The site includes a transition information fact sheet for families, worksheets for youth and families, age specific teaching sheets, timelines, a two-page healthcare transition checklist, information about education and employment, questions to ask potential adult physicians, and links to other resources.

Family Village: Transition & the Internet – www.familyvillage.wisc.edu/sp/TRANS.HTML

Sponsored by the Waisman Center (see below), the Joseph P. Kennedy Jr. Foundation, and the Mitsubishi Electric America Foundation and housed at the University of Wisconsin-Madison,

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Family Village is a global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them with services and support. This web site has a comprehensive and wide variety of links to other web resources pertaining to transition.

Got Transition? – <http://www.gottransition.org/>

A national resource for health care professionals, families, youth, and state policy makers focusing on a young adult's transition from pediatric to adult health care. The site serves as the basis for information exchange about health care transition, particularly pertaining to youth with special health care needs. Supported by cooperative agreement U39MC18176 HRSA/ USMCHB, Got Transition? is a program of the Center for Medical Home Improvement at Crotched Mountain Foundation. Information is available in many languages.

Health Care Transitions – <http://hctransitions.ichp.ufl.edu/hct-promo/>

Sponsored by the Institute on Child Health Policy at the University of Florida and supported through a grant from the National Institute on Disability and Rehabilitation Research (NIDRR), the site includes research about promising practices in transition and provides a variety of other transition resources, including provider and youth/family resource manuals, a comprehensive bibliography of transition publications, and links to information specifically for people with cystic fibrosis or bleeding disorders.

Healthy & Ready to Work National Center – <http://www.mchbhrtw.org/>

Sponsored by and funded through a cooperative agreement from the Integrated Services Branch, Division of Services for Children with Special Health Care Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Service Administration (HRSA), Department of Health and Human Services (DHHS), the site provides information and connections to health and transition expertise nationwide and focuses on understanding systems, access to quality health care, and increasing the involvement of youth. It also includes provider preparation plus tools and resources needed to make more informed choices!

I'm Determined – <http://www.imdetermined.org>

I'm Determined, a project developed and sponsored by the Virginia Department of Education's Training and Technical Assistance Centers. It focuses on providing direct instruction, models, and opportunities to practice skills associated with self-determined behavior beginning at the elementary level and continuing through the student's educational career. It is about building self-determination and self-advocacy skills in youth, as well as strategies for supporting youth in running their own IEPs. There are lesson plans, checklists, curricula, and more.

Leadership Education in Adolescent Health (LEAH) –

<http://www.bcm.edu/pediatrics/sportsmedicine/leahhome> Sponsored through the Baylor College of Medicine Department of Pediatrics Adolescent Medicine and Sports Medicine (Houston, TX), LEAH

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is a specialized training program in adolescent health care that focuses on an interdisciplinary team approach to healthcare. Faculty members represent the disciplines of medicine, nursing, nutrition, psychology, public health, and social work. This program stresses excellence in adolescent health and finding ways to meet the healthcare needs of adolescents.

National Center on Secondary Education and Transition – www.ncset.org/default.asp

Sponsored by National Center on Secondary Education and Transition (NCSET) and affiliated with the Institute on Community Integration at the University of Minnesota, NCSET coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities in order to create opportunities for youth to achieve successful futures. Many resources for youth and families are available in both English and Spanish.

National Dissemination Center on Children with Disabilities (NICHCY) –

http://www.nichcy.org/EducateChildren/transition_adulthood/Pages/Default.aspx

This Web page is made possible through funding from the Office of Special Education Programs (OSEP), U.S. Department of Education. The “Transition to Adulthood” Web pages include links to Transitions 101, Transition Resources for Parents, Transition Resources for Students, Transition Resources for

Professionals (mostly educators and school administrators), and Transition and Specific Disabilities. They provide a wealth of well-organized resources from a variety of nationally-recognized sources.

PACER Center – <http://www.pacer.org/index.asp>

Founded in 1977 and based in Minnesota, the Parent Advocacy Coalition for Educational Rights (PACER) Center was created by parents of children and youth with disabilities to help other parents and families facing similar challenges. Its mission is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents. Site includes a comprehensive catalogue of both free and for purchase publications.

Partners Resource Network (Texas) – <http://www.partnerstx.org/TxTransition/>

Partners Resource Network (PRN) is a non-profit agency that operates the Texas statewide network of Parent Training and Information Centers (PTI's) funded by the US Department of Education, Office of Special Education Programs (OSEP). Their mission is to empower parents of children and youth with disabilities in their roles as parents, decision makers, and advocates for their children and to promote partnerships among parents and professionals. The transition page includes information about issues including [postsecondary education](#), [non-degree postsecondary options](#), and employment. The site also includes some resources in Spanish and other languages.

Texas Project FIRST -- <http://www.texasprojectfirst.org/>

Created by parents, for parents, this web site is a project of the Texas Education Agency (TEA) and is committed to providing accurate and consistent information to parents & families of students

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with disabilities. Its information is organized according to age groups and is available in Spanish as well as English. People can register to receive email updates as new information is added to the site.

Transition Matters – www.transitionmatters.org/

Transition Matters is a website published and maintained by James E. Williams, Jr., a person with Asperger's Syndrome and pervasive developmental delay (PDD) attending Sam Houston State University preparing for a career as a special education teacher. The web site contains documents or links that pertain to Post-Secondary Transition and Asperger's Syndrome/High Functioning Autism.

Waisman Center – <http://www.waisman.wisc.edu/hrtw/index.html>

Sponsored by the University of Wisconsin at Madison, the Waisman Center Wisconsin Healthy and Ready to Work site describes the Title V transition activities in Wisconsin. Among its resources are links to other sites with topics that include assistive technology, transition planning and checklists, benefits and financial planning, community living, education, employment, health and health care, housing, mental health, relationships, sexuality, and many more.

Wrightslaw – <http://www.wrightslaw.com>

Wrightslaw provides accurate, reliable information about special education law, education law, and advocacy for children with disabilities. The site can be used by young adults, parents, educators, advocates, and attorneys. There are search capabilities found within links to advocacy libraries and law libraries, with thousands of articles, cases, and free resources about many topics. Though this is a commercial site, most of its information is available at no charge.

Youth on the Move – <http://www.youth-move.org/>

Youth on the Move is a project of the Institute for Community Inclusion at the University of Massachusetts Boston that is designed to provide information, strategies, and resources to transition teachers, counselors, family members, and community providers to guide youth in transition. The site offers age-based timelines, personal stories, and news and resources relevant to transition.

Web Resources about Inclusion and Community Integration

Institute for Community Inclusion – www.communityinclusion.org/

Sponsored by the Institute for Community Inclusion based at the University of Massachusetts Boston with offices at Children's Hospital Boston, the mission of the Institute is to support the rights of children and adults with disabilities to participate in all aspects of the community. Key interest areas include: employing people with disabilities in community settings; supporting children and young adults with special health care needs; accessing general education, and transition from school to adult life; expanding local recreation and school activities to include people with disabilities; promoting technology that aids participation in school/community/work activities; building organizations' abilities to serve culturally diverse people with disabilities; and examining the impact of national and state policies on people with disabilities and their families.

Institute on Community Integration – ici.umn.edu/

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Sponsored by the Institute on Community Integration in the College of Education and Human Development at the University of Minnesota, the mission of this Institute is to improve the community services and social supports available to individuals with developmental and other disabilities, and their families throughout the United States and abroad through research, professional training, technical assistance and publishing activities. Publications include newsletters, resource guides, curricula, reports and brochures.

National Center for Cultural Competence – <http://gucchd.georgetown.edu/nccc/>

Supported by the Georgetown University Center for Child Development, the mission of the National Center for Cultural Competence (NCCC) is to increase the capacity of health and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems. The NCCC embraces a conceptual framework and model for achieving cultural competence. The site has a Spanish-language portal and includes various topics related to family and youth perspectives on service delivery to children and youth with special health needs and their families.

► **Transition Articles and Publications available on the Web**

A Family Handbook on Future Planning

http://internet.dscc.uic.edu/forms/psu/Future_Planning_Family_Handbook_2003.pdf

Edited by Sharon Davis, PhD, and published by The ARC of the United States in collaboration with the Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago this is a guide to help families develop a future plan for their sons or daughters who have cognitive, intellectual or developmental disabilities. It provides information about personal, financial and legal protections for children after the parents either die or can no longer provide care or support. *A Family Handbook on Future Planning* is not designed to be a “do-it-yourself” guide to will writing, trust development and other legal processes. Instead, it is designed to help families review and inventory the needs and strengths of a family member who is disabled, determine what should be in a plan, and then locate qualified professionals and resources to finalize the plan.

The 411 on Disability Disclosure: A Workbook for Youth with Disabilities

http://www.ncwd-youth.info/resources_&Publications/411.html

Published by the National Collaborative on Workforce and Disability/Youth, housed at the Institute for Educational Leadership in Washington, DC, the workbook is designed for youth and adults working with them to learn about disability disclosure. This workbook helps young people make informed decisions about whether or not to disclose their disability and understand how that decision may impact their education, employment, and social lives. Based on the premise that

disclosure is a very personal decision, the Workbook helps young people think about and practice disclosing their disability. The units provide activities to help youth make important disclosure decisions such as: Whether to disclose? What to disclose? When to disclose? Who to tell? How much to tell?

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Tips for Parents and Children on Making the Transition

<http://www.telability.org/handouts/TelAbilityHandoutHappyHealthyandIndependent.pdf>

This is a two-page listing on the Telability web site. Telability is an interdisciplinary program based at the University of North Carolina that uses telecommunications to improve the lives children with disabilities. The listing includes suggestions on transition topics, including “How to Get There,” “Staying Happy,” “Staying Healthy,” and “Learning to be Independent.”

Transition Information Sheet for Families

<http://internet.dsc.uic.edu/forms/psu/0592.pdf>

Developed by the University of Illinois at Chicago, this is a one-page overview of key medical transition issues and questions. It's designed to help a parent prepare and plan a child's move from pediatric or child-centered to adult-centered health care systems.

“Transition to Adulthood: The Important Role of the Pediatrician”

Olsen, Donna G. and Nancy L. Swigonski. *Pediatrics* 11:3, March 2004, pp e159-e162.

<http://pediatrics.aappublications.org/cgi/content/full/113/3/e159>

This article, written by a parent of 2 youths with special health care needs and a pediatrician, builds on the Medical Home framework to give concrete examples of what physicians and families can and should do to prepare families for transition(s). The article consists of 3 parts. The first part is an introduction giving an overview of the importance of transition. The second part, "Developing a Life (not Illness) Plan: Begin With the End in Mind," emphasizes that no matter how challenging the disability or compromising the chronic illness, parents owe it to their children to risk thinking about the future and beginning to help them develop a life (not illness) plan. The third part, "With a Little Help from My Friends," looks at how linking families with other parents, young adults, and adults living with disabilities and serious chronic illness can be a source of information to both families and physicians as they plan for the future.

What's HEALTH Got To Do With TRANSITION?

http://health.usf.edu/medicine/pediatrics/ad_med/resources.htm

This site links to A Health Care Transition Information and Resource Guide and a Student Curriculum authored by Janet Hess, et al, in conjunction with the School District of Hillsborough County and the University of Florida, commissioned, funded, and sponsored by the Florida Developmental Disabilities Council, Inc., and produced through funding provided by the U.S. Department of Health and Human Services, Administration for Developmental Disabilities. Though the Information and Resource Guide speaks to resources mostly available in Florida, it includes useful information that could apply to any state. The Information and Resource Guide also is available in Spanish, Braille, and large print.

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